

**Minutes of the
Norfolk All Age Autism Partnership Board (NAPB)**

Held on: Tuesday 14 March 2023, 10:00 – 12:00pm

Venue: Microsoft Teams

Please note: These notes represent an overview summary of this meeting rather than a verbatim transcript.

Name of Attendee	Organisation and or Role
Adrian Grant	Co-Chair
Trevor Key	Co-Chair
Maxine Blocksidge	Senior Adviser SEND (NCC)
Sharon Brooks	Carers Voice for Norfolk & Waveney
Stephen Durrance	Autistic Adult
Alison Furniss	Voluntary Sector Representative Family Voice
Rachel Gates	Senior Program Manager (ICB)
Lee Gibbons	Partnership Coordinator / Note Taker Voluntary Sector Representative, Autism Partnership Coordinator, ASD Helping Hands Engagement Working Group Lead
Andy Hudson	Head of Personalisation, Quality of Care for LD and Autism (ICB)
Caroline Williams	Head of Communications and Engagement, Healthwatch
Caron Ager	Attending on behalf of Rachel Gates
Rebecca Crossley	
Tracey Walton	Autism Commissioning Manager (NCC)
Amanda Johnson	Business Lead in the Adult Social (NCC)
Karen Dures	Strategic Business Lead - Autism Adult Social Services (NCC)
Maria Karretti	Safeguarding Adults Clinical Advisor for Autism and Learning Disabilities
Joanna Yellon	NHS England (East) locality director
Andrew Macey	Parent/Carer

Apologies Received	Organisation and or Role
Ryan Hardy	NCC
James Bullion	Co-chair; Executive Director Adult Social Services, Norfolk County Council (NCC)
Catherine Haig	Autism Service Norfolk, NCH&C
Claire Jones	Local Offer Manager – Family Help and SEND (NCC)
Stephanie Summers	NCHC - Clinical Psychologist
Richard Peat	Parent Carer
Bethany Slaughter	Norfolk Constabulary
Tina Allen	Autism Service Norfolk

Presenters	Organisation and or Role

Agenda Item 1	Welcome, Introduction & Approval of minutes and action log	Action and Due Date
1.1	Welcome and introductions made. Communication prompts posted to the Teams Chat window, and their use explained. No reasonable adjustments were requested. Members reported no declaration of interest. Minutes and action log approved by the Norfolk Autism Partnership Board (NAPB)	
1.2	Action: Arrange for Pathological Demand Avoidance update	Currently on Hold
1.3	Action: Pass details of those who wish to be involved in further events regarding the Early Support Service to be put in touch with Tracey Walton.	Lee Gibbons Completed
1.4	Action: Anyone interested in being part of the task and finish group please email Lee Gibbons	All Completed
1.5	Action: Lee Gibbons and Evy Coe, to work together to make sure the NAPB website meets accessibility criteria	Lee Gibbons Completed
1.6	Action: Tracey Walton and Rebecca Crossley to liaise to identify these gaps and which colleagues would be best to attend the Neurodevelopmental Disorder Stakeholder meeting.	Tracey Walton / Rebecca Crossley Completed
1.7	Action: Rebecca Crossley to introduce Lee Gibbons to those who can present information on the ratification process and risks	Rebecca Crossley / Lee Gibbons Ongoing

1.8	Action: Maxine asked to send round more information on SENDfest when it is available. Can forward to Norfolk Autism Partnership to facilitate this.	Maxine Blocksidge Completed
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Agenda Item 2	Updates on the Diagnostic waiting times	Action and Due Date
2.1	Tracey Walton gave us an update on the diagnostic waiting times for Norfolk	
2.2	<p>Adult wait times</p> <p>In the past 12 months there have been 915 referrals into the service.</p> <p>With monthly average of 76. In Jan 2023 there were 55 referrals.</p> <p>In January 2023 there 740 adults waiting for an assessment (20% decrease since last reporting)</p> <p>Over the past 12 months there have been:</p> <ul style="list-style-type: none"> • 866 completed assessments <ul style="list-style-type: none"> ○ 185 by autism Service Norfolk (17% increase since last reporting) ○ 781 by independent providers (54% increase since last reporting) <p>This report are the numbers at the end of January 2023. Last reported October 2022</p>	
2.3	<p>Waiting times for first appointment:</p> <ul style="list-style-type: none"> • 3 waiting over 200 weeks. • 81 waiting between 104-200 weeks. • 169 waiting between 52 and 104 weeks. • 287 waiting between 18-52 weeks. • 200 waiting under 18 weeks <p>It was noted that those waiting over 200 weeks was not a true reflection due to how the services measures waiting times for those that disengage then reengage.</p>	
2.4	Although the providers have been successful in reducing number of people waiting for assessment, this number is likely due to increase due to demand outmatching assessments carried out.	

2.5	<p>Norfolk County Commissioners are working with Autism Service Norfolk to explore ways to increase number of assessments.</p> <p>Once options have been identified Autism Service Norfolk and Norfolk County Council would like to work with autistic adults and the Norfolk Autism Partnership board to produce a co-produced approach.</p>	
2.6	<p>Children and Young People wait times.</p> <p>4831 children on the waiting list as of Jan 2023</p> <p>Average wait time to be seen is 40 weeks</p> <p>2910 children and young people waiting 1-2 years for an active assessment</p> <p>Waits for discharge (being given the results of an assessment) are up to 4 years</p>	
2.7	<p>Waiting times for first appointment:</p> <ul style="list-style-type: none"> • 0 waiting over 200 weeks. • 0 waiting between 104-200 weeks. • 202 waiting between 52 and 104 weeks. • 551 waiting between 18-52 weeks. • 497 waiting under 18 weeks 	
2.8	<p>Next steps to help alleviate the waiting list where provided:</p> <ul style="list-style-type: none"> • Implement waiting list initiative (awaiting further details) • Review of the clinical pathway • Work with NSFT and Autism Service Norfolk to review the 18+ case load. (People who are unlikely to be discharged before their 18 birthday) 	
2.9	<p>Adult Pathway</p> <p>Question: Is there an average waiting time for initial appointment?</p> <p>Answer: Was unable to provide at the meeting but since has been confirmed as: 62 Weeks</p>	
2.10	<p>Adult Pathway</p> <p>Question: Do we know how many assessments lead to a diagnosis of autism?</p>	

	<p>Answer: Was unable to provide at the meeting but since then have been confirmed as: 91% receive a positive diagnosis.</p>	
2.11	<p>Children and Young People Pathway</p> <p>Question: What is meant by discharge? What are the actual barriers?</p> <p>Answer: Discharge is when a person has been given a negative or positive result to their autism assessment. Barriers include:</p> <ul style="list-style-type: none"> • Large amounts of referrals • Issues around the ADOS2 assessment. Needing to see a person in two locations. <p>It was mentioned that some providers can complete assessments with in 1 week. RC has concerns around providers that are able to do this as she has carried out inspections on some independent providers and they have not been carrying out the ADOS 2 assessment and their diagnosis assessments are not NICE compliant.</p>	
2.12	<p>Adult Pathway</p> <p>Question: Is the funding used to outsource assessments fixed?</p> <p>Answer: The funding currently in place will stop on the 31 March 2023. No plans to reinstate funding. Work is being carried out at Autism Service Norfolk to look at possible options to manage the waiting list.</p> <p>A member of the board comments that more money needs to be provided to the pathway to prevent waiting times increasing greatly.</p>	
2.13	<p>Question: Where do funding decision get signed off and what is the role of the Norfolk Autism Partnership in this?</p> <p>Answer: It was explained that the Norfolk Autism Partnership board does not have final say or sign off on funding decisions. The Norfolk Autism Partnership board is a collective forum that aims to influence and feedback on documents and decisions. It is also used as a platform to promote and conduct co-production. The final sign off of documents is by the ICB (Integrated Care Board) or NCC (Norfolk County Council).</p>	

	A member commented that the Norfolk Autism Partnership Board should have sight of plans and any thinking that effects those with autism in Norfolk before signing off	
2.14	<p>Children and Young People Pathway</p> <p>Question: Are parents aware of the independent providers in Norfolk and the risks of paying privately?</p> <p>Answer: The ICB are currently working on a document/guide for parents seeking a private assessment. It will include things to expect, questions to ask and how the assessment should be conducted in line with NICE guidelines.</p> <p>There is some information on the Local offer website regarding Private neurodevelopmental assessments, which can be found here: https://tinyurl.com/43trcnse</p> <p>There is a need to understand why parents are seeking a diagnosis for their children/young people. Is it for support in school placements/ medication?</p>	
2.15	<p>Action: Consider a piece of work to find out the answers to ‘what motivates you as a parent/carer to seek a diagnosis for your child/young person?’</p> <p>Support from Carer’s voice to facilitate this piece of work if required.</p>	<p>Diagnosis WG</p> <p>Ongoing</p>

Agenda Item 3	Update on new early support service consultation	Action and Due Date
3.1	Tracey Walton gave an update on the co-production work being carried out for the new early support service	
3.2	<p>This new service will aim to:</p> <ul style="list-style-type: none"> • Support autistic adults at an earlier stage providing short term support to meet care needs • Reduce the number of autistic adults needing a formal care assessment 	
3.3	The pre co-production work involved the Norfolk Autism Partnership and the Making it Real Board	
3.4	<p>Several co-production tools were developed to ensure a wide range of views and feedback was gathered. This included:</p> <ul style="list-style-type: none"> • Face to face sessions 	

	<ul style="list-style-type: none"> • Telephone calls • Virtual meetings • Feedback work booklets 	
3.5	<p>Co-production events including autistic people, their families and carers that have been carried out or planned are:</p> <p>14 Dec 2022: Norfolk Autism Forum to seek the views of members.</p> <p>2 Feb 2023: Norfolk Diagnosis Working Group to seek the views of members.</p> <p>Feb – April 2023: Workbook for those who don't like groups or 1:1 conversation.</p> <p>Feb – April 2023: Autism library sessions, to offer an opportunity to talk to us. Covering Wroxham, Norwich, Thetford, Fakenham, King's Lynn, Gt Yarmouth, Wymondham and Acle.</p> <p>27 Feb 2023: Microsoft Teams autism conversation to design the service.</p> <p>13 Mar–7 Apr 2023: Design, test and distribute a coproduced questionnaire.</p>	
3.6	<p>Co-production events with Norfolk County Council and Wider partners that have been completed are:</p> <p>14 Dec 2022:Norfolk County Council Autism Champions Forum.</p> <p>Feb–Apr 2023: Learning Disability and Mental Health Operational Locality Teams, Preparing for Adult Life team, Adult Social Care Front door.</p> <p>13 Mar–7 Apr 2023: Distribute questionnaire.</p> <p>March 2023: Wider partnership views (NCHC, NSFT).</p> <p>March 2023: Voluntary, Community and Social Enterprise conversations.</p>	
3.7	<p>The four common these found in these co production events are:</p> <ul style="list-style-type: none"> • Support Worker • A link worker or navigator • A drop in service • Peer support service 	

3.8	<p>A questionnaire has been developed that aims to identify:</p> <ul style="list-style-type: none"> • if these four themes are important to autistic people and if so, in what priority order. • what else is important, have we missed anything? <p>This questionnaire is live from Monday 13 March 2023 to Sunday 9 April 2023, and can be found on the Norfolk Autism Partnership website and the Norfolk County Council Website.</p>	
3.9	Once the questionnaire has been closed Tracey Walton will seek the help of autistic people to analyse the questionnaire to understand what is important to autistic People.	
3.10	Action: Asked to promote questionnaire through Norfolk Autism Partnership communication streams.	Lee Gibbons ASAP (Done)

Agenda Item 4	Introduction to Karen Dures	Action and Due Date
4.1	Karen Dures introduced herself as the newly appointed Strategic Business Lead – Autism for Adult social services	
4.2	<p>Karen explained the purpose of her role.</p> <ul style="list-style-type: none"> • Providing county-wide leadership in Adult Social Services to improve how we support autistic adults. • Represent Adult Social Services at the Norfolk Autism Partnership Board and work with autistic adults, their families and partner organisations to achieve the aims of the Norfolk All Age Autism Strategy. • Work with commissioners, Health colleagues and other partners to influence the development of services and promote good practice. 	
4.3	<p>Karen Explained how she would plan on doing this by:</p> <ul style="list-style-type: none"> • Continuing working with the autism commissioning manager to develop a new service, which will provide short-term support 	

	<p>for autistic people who would benefit from this.</p> <ul style="list-style-type: none"> • Talk to autistic people, families and social care staff to understand more about what needs to change. • Work to understand how many people Adult Social Services is currently working with and what their needs are – especially unmet needs. • Work with autistic people and social care staff to create resources and guidance to improve autistic people’s experience of contact with Adult Social Services. • Local and regional meetings to work with Health and partner organisations to join up and improve support and learn from other areas. 	
4.4	Karen can be contacted on her email address which is karen.dures@norfolk.gov.uk	

Agenda Item 5	Update on the Norfolk Autism Forum	Action and Due Date
5.1	Lee Gibbons gave an update on the Autism Norfolk Forum.	
5.2	The next forum will be held on the Wednesday 22 March 2023 with the theme of Advocacy. This will be held via Zoom.	
5.3	<p>There are two guest speakers at the next Autism Norfolk Forum:</p> <ul style="list-style-type: none"> • Robert Cooper - Commissioning Programme Manager Mental Health (Norfolk County Council) • Nicola Cogdell – Independent Advocate (PohWer) 	
5.4	You can register for the forum at: You can register at : https://tinyurl.com/236p28sp	

Agenda Item 6	Co Chair Update – Disability Related Expenses	Action and Due Date.
6.1	Trevor Key (Co-Chair) gave us an update on the work he has been involved with on Disability Related Expenses .	

6.2	<p>Trevor briefly explained what disability related expenses are and who can claim for these.</p> <p>You may be able to claim disability related expenses if:</p> <ul style="list-style-type: none"> • You are aged 18 or above. • Norfolk County Council provides care for you. • You pay towards the cost of this care. 	
6.3	There is a new disability related expenses webpage on the Norfolk County Council website that was co-produced along side the Making it Real Board	
6.4	The new website can be found at : www.norfolk.gov.uk/dre	

Agenda Item 7	Forward Working Plans	Action and Due Date.
7.1	Lee Gibbons gave us an update on the Forward Working plans for the Norfolk Autism Partnership	
7.2	Since the last board meeting the task and finish group has met twice. They looked at the service specification given to ASD Helping Hands when they took over the running of the Partnership boards. This service specification laid out what ASD helping Hands needs to report on during their running of the partnership.	
7.3	The task and finish group have produced an initial plan and asked for their feedback on the structure from the members of the Norfolk Autism Partnership Board.	
7.4	Lee Gibbons explained the diagram and that they wanted to introduce a new steering group into the partnership structure that was made up mainly of autistic people and their families and carers. The aim of this steering group is to take all the information that is gathered from the website, the Autism Forum Norfolk as well as other sources and decide on the priorities that the board need to consider.	
7.5	It is hoped that this steering group will empower autistic people involved in the partnership to truly say what is and isn't working and to also bring the 'real life' issues that affect them everyday to the attention of the board.	
7.6	Concerns around 'where does the strategy fit' and what does the Norfolk Autism Partnership board actually do to help these prioritise' were voiced by some members	

7.7	Agreement was made by the Autism Partnership Board to move forward with this new structure	
7.8	Action: To draft/adjust the terms of reference to reflect the new Steering group and ways of working	Task and Finish Group 16 May 2023
7.9	Action: To bring the newly drafted Terms of Reference to the next board	Lee Gibbons 16 May 2023
7.10	Action: Anyone wanting to take part in this task and finish group to email Lee Gibbons on contact@norfollkautismpartnership.org.uk	All 27 March 2023

Agenda Item 6	Any other business	Action and Due Date.
6.1	STRATA study - SerTRaline for Anxiety in adults with a diagnosis of autism Maria Karretti provided an overview of the study. They are inviting Adults with a Diagnosis of autism to participate in a trial to see if a medication call Sertraline can help autistic adults with Anxiety	
6.2	Lee Gibbons asked the partnership if this is something that they wished to promote on our newsletter/website and/or social media pages. Agreed following action below	
6.3	Action: Maria Karretti and Lee Gibbons to work together to form some wording explaining the study before circulating to our members	Maria Karretti / Lee Gibbons 16 May 2023
6.4	Maxine Blocksidge told us about an Autism Acceptance week event that the SEND Norfolk are holding and ask the partnership to distribute flyer and information. Action: Lee Gibbons to send out flyer/information to partnership members.	Lee Gibbons 23 March 2023
6.5	The Co-chairs thanked everyone for their attendance and closed the meeting.	

Date, time and location of next meeting
Norfolk Autism Forum: 22nd March 2023 – Online via Zoom Norfolk Autism Partnership Board: Tuesday 16th May 2023 – Online via Teams

Glossary

ANF:	Autism Norfolk Forum
ASD:	Autism Spectrum Disorder
CQC:	Care Quality Commission
CCG:	Clinical Commissioning Groups
FOI:	Freedom of Information
GDPR:	General Data Protection Regulations
ICB:	Integrated Care Board
LDP:	Learning Disability Partnership
LDPB:	Learning Disability Partnership Board
NAP:	Norfolk Autism Partnership
NAPB:	Norfolk Autism Partnership Board
NAS:	National Autistic Society
NCC:	Norfolk County Council
NCH&C:	Norfolk Community Health and Care
N&SFT:	Norfolk and Suffolk Foundation Trust
SEND:	Special Educational Need and Disabilities
UEA:	University of East Anglia
WAW:	World Autism Week
WG Lead:	Working Group Lead